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National report on patient outcomes in palliative care in Australia, July - December 2014

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Abstract

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) Standards for Providing Quality Palliative Care for all Australians. This is achieved via the PCOC dataset; a multi-purpose framework designed to: * provide clinicians with an approach to systematically assess individual patient experiences, * define a common clinical language to streamline communication between palliative care providers and * facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

Keywords

december, july, australia, care, palliative, outcomes, patient, 2014, report, national

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PCOC

palliative care
outcomes collaboration

National Report on Patient Outcomes in Palliative Care in Australia

July – December 2014

March 2015

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www.pcoc.org.au

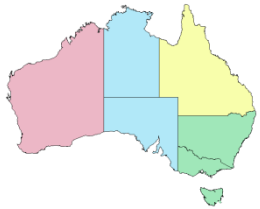
About the Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care for all Australians*. This is achieved via the PCOC dataset; a multi-purpose framework designed to:

- provide clinicians with an approach to systematically assess individual patient experiences,
- define a common clinical language to streamline communication between palliative care providers and
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

The PCOC dataset includes the clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

PCOC has divided Australia into four zones for the purpose of engaging with palliative care service providers. Each zone is represented by a chief investigator from one of the collaborative centres. The four PCOC zones and their respective chief investigators are:



Central Zone	**Professor Kathy Eagar**, Australian Health Services Research Institute, University of Wollongong
North Zone	**Professor Patsy Yates**, Institute of Health and Biomedical Innovation, Queensland University of Technology
South Zone	**Professor David Currow**, Department of Palliative and Supportive Services, Flinders University
West Zone	**Dr Claire Johnson**, Cancer and Palliative Care Research and Evaluation Unit, University of WA

Each zone is also represented by one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement. The national team, located within the Australian Health Services Research Institute at the University of Wollongong, coordinates the patient outcomes reporting, education program, and quality activities across the four zones.

If you would like more information or have any queries about this report please contact your local quality improvement facilitator or contact the national office at pcoc@uow.edu.au or phone (02) 4221 4411.

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this PCOC report, data submitted for the July to December 2014 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

Patient outcomes are reported for a total of 18,310 patients, with 23,449 episodes of care and 53,467 palliative care phases. The information included in this report is determined by a data scoping method. See Appendix A for more information on the data included in this report.

The national figures are based on information submitted by 95 services, of which:

- 53 are inpatient services. Inpatient services include patients who have been seen in designated palliative care beds as well as non-designated bed consultations.
- 27 are community services. These services include primarily patients seen in the community as well as some patients with ambulatory/clinic episodes.
- 15 are services with both inpatient and community settings.

A full list of the services included in the national figures can be found at www.pcoc.org.au.

Interpretation hint:

Some tables throughout this report may be incomplete. This is because some items may not be applicable to all services or it may be due to data quality issues.

Please use the following key when interpreting the tables:

na **The item is not applicable.**
u **The item was unavailable.**
s **The item was suppressed due to insufficient data as there was less than 10 observations.**

Section 1 Benchmark summary

1.1 Australian outcomes at a glance

Table 1 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			Score (%)	Benchmark Met?	Score (%)	Benchmark Met?
1. Time from ready for care to episode start	Benchmark 1: Patients episode commences on the day of, or the day after date ready for care	90%	96.3	Yes	87.1	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	84.2	No	74.9	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	90.9	Yes	84.8	No
	Benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	57.1	No	50.1	No
	Benchmark 3.3: SAS Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end	90%	88.1	No	82.7	No
	Benchmark 3.4: SAS Patients with moderate/severe distress from pain at phase start, with absent/mild at phase end	60%	52.8	No	45.4	No

Table 2 Summary of outcome measure 4: Average improvement on the 2014 baseline national average (X-CAS)

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	0.00	Yes
	Benchmark 4.2: Other symptoms	0.02	Yes
	Benchmark 4.3: Family/carer	0.01	Yes
	Benchmark 4.4: Psychological/spiritual	0.01	Yes
SAS	Benchmark 4.5: Pain	-0.01	No
	Benchmark 4.6: Nausea	0.02	Yes
	Benchmark 4.7: Breathing problems	0.02	Yes
	Benchmark 4.8: Bowel problems	0.03	Yes

The benchmark for outcome measure 4 is zero.

For more information on the outcome measures and benchmarks, see Section 2.

1.2 National benchmark profiles

In this section, the national profiles for selected benchmarks are split by setting (inpatient or community) and presented graphically.

The selected benchmarks included are:

- Benchmark 1 Patients episode commences on the day of or the day after date ready for care
- Benchmark 2 Patients in the unstable phase for 3 days or less
- Benchmark 3.1 PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end
- Benchmark 3.2 PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end
- Benchmark 3.3 SAS: Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end
- Benchmark 3.4 SAS: Patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end

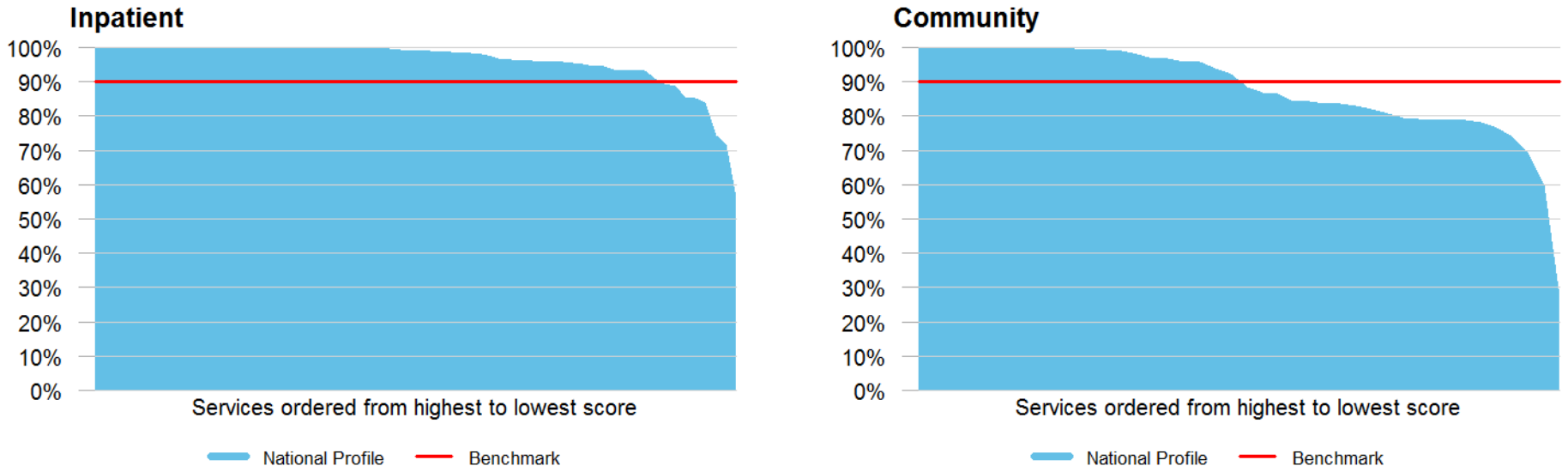
Interpretation hint:

The national profile graphs on the following pages allow services to see how they are performing in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure.

The red line on the graph indicates the benchmark for that outcome measure.

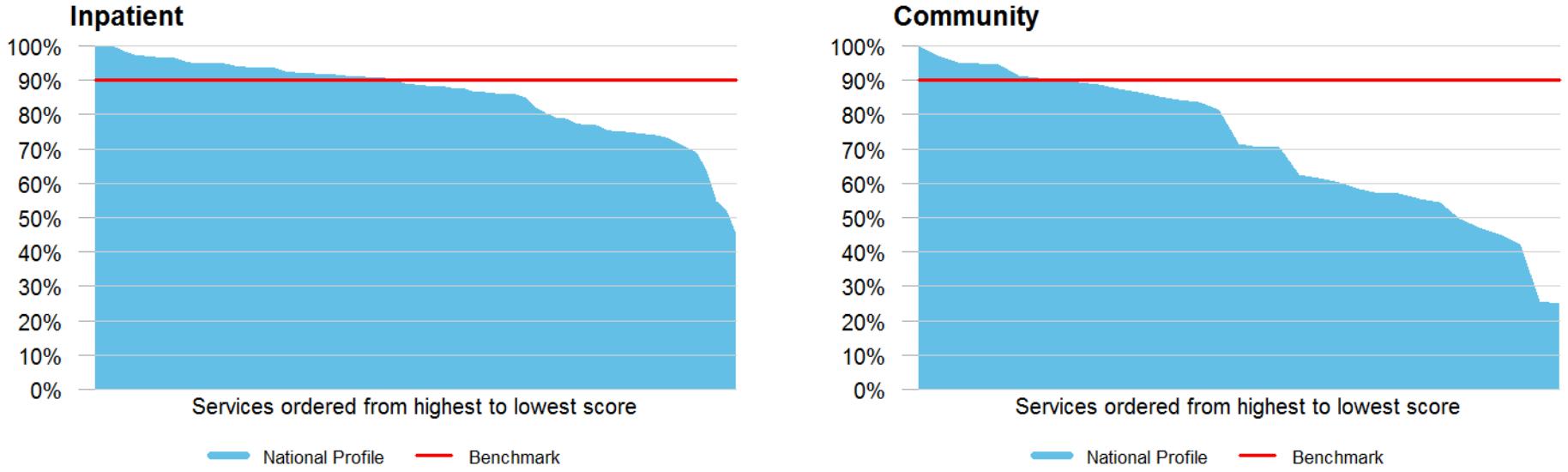
Outcome measure 1 – Time from date ready for care to episode start

Figure 1 Percentage of patients with episodes started on the day of, or the day after date ready for care



Outcome measure 2 – Time in unstable phase

Figure 2 Percentage of patients in the unstable phase for 3 days or less



Outcome measure 3 – Change in pain

Figure 3 PCPSS: Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end

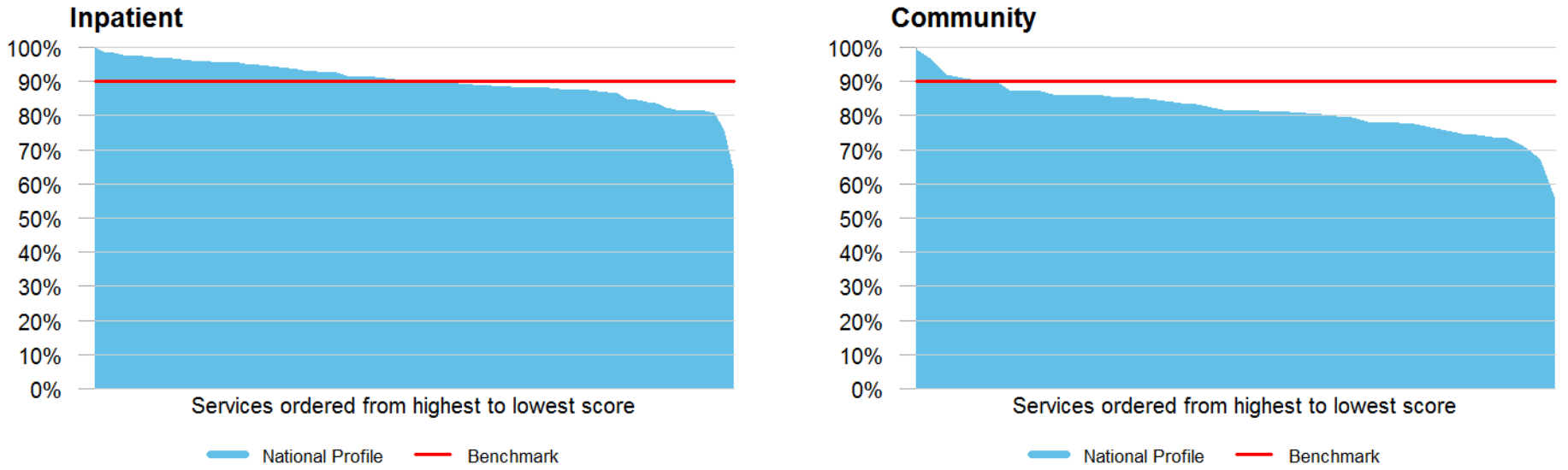


Figure 4 PCPSS: Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end

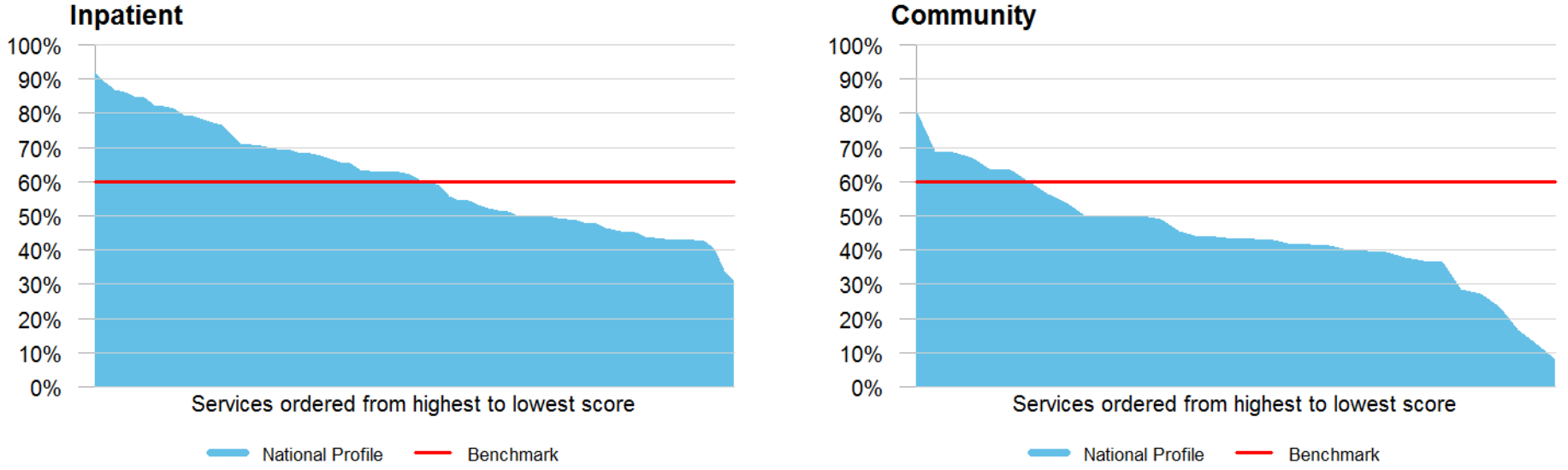


Figure 5 SAS: Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end

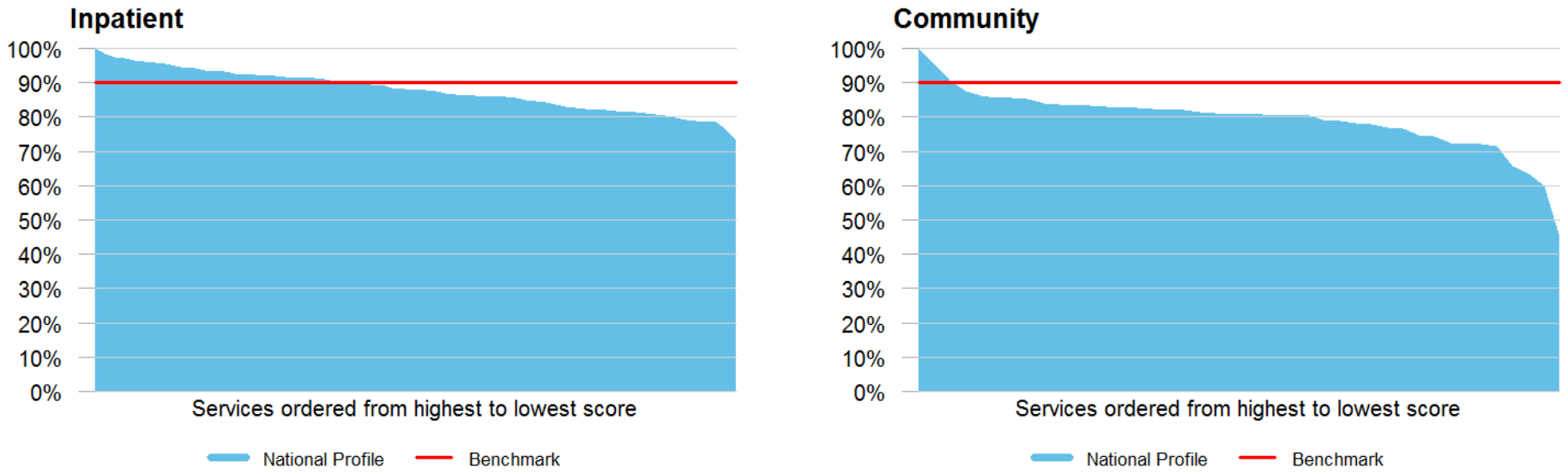
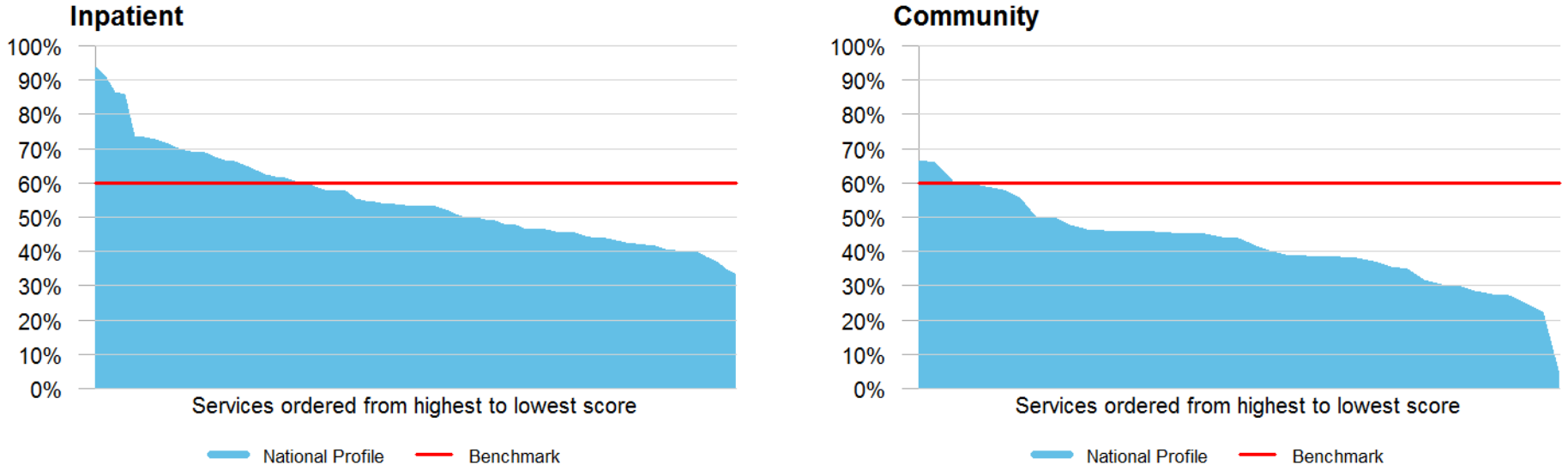


Figure 6 SAS: Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end



Section 2 Outcome measures in detail

2.1 Outcome measure 1 – Time from date ready for care to episode start

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (all services are being benchmarked together).

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following date ready for care.

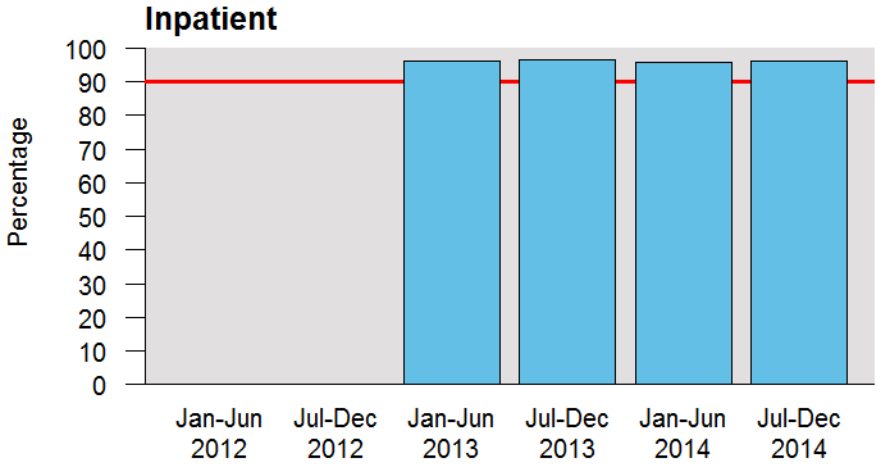
Table 3 Time from date ready for care to episode start by setting

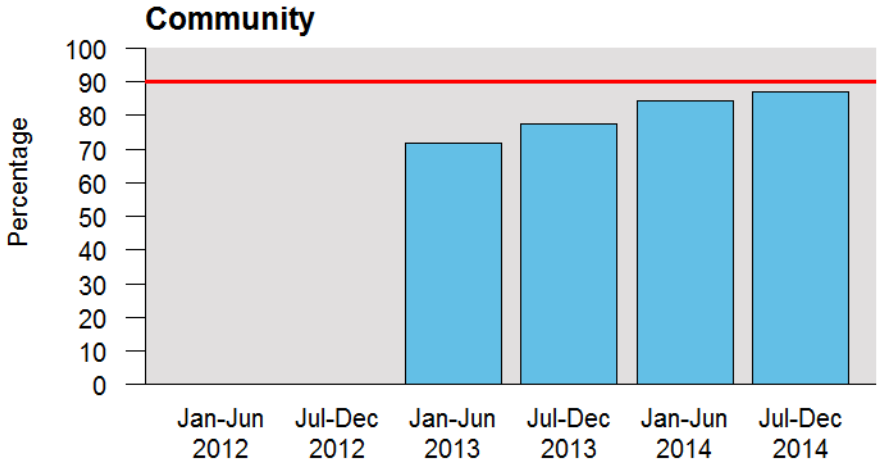
Time (in days)	Inpatient		Community	
	N	%	N	%
Same day	10,032	89.5	8,240	82.2
Following day	768	6.8	493	4.9
2-7 days	380	3.4	953	9.5
8-14 days	22	0.2	203	2.0
Greater than 14 days	12	0.1	140	1.4
Average	1.1	na	1.9	na
Median	1	na	1	na

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Interpretation hint:
Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.

Figure 7 Percentage of episodes that met outcome measure 1 over time





2.2 Outcome measure 2 – Time in unstable phase

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and/or
- a patient experiences a rapid increase in the severity of an existing problem, and/or
- a patient's family/carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

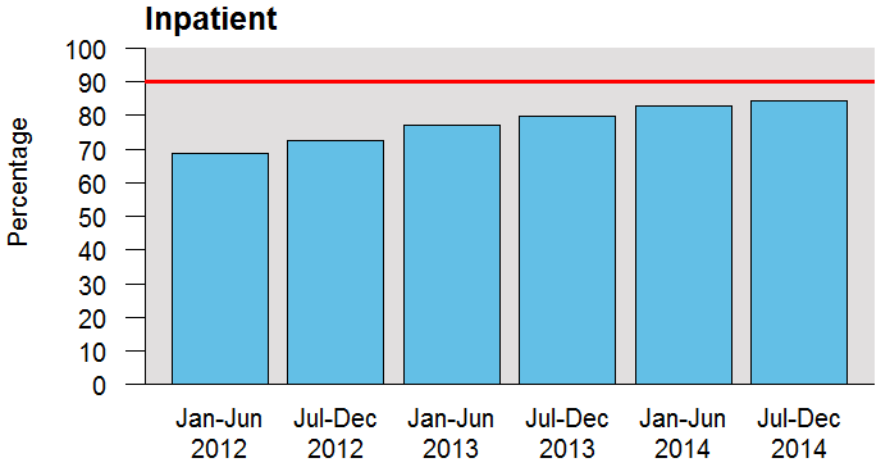
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom/crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

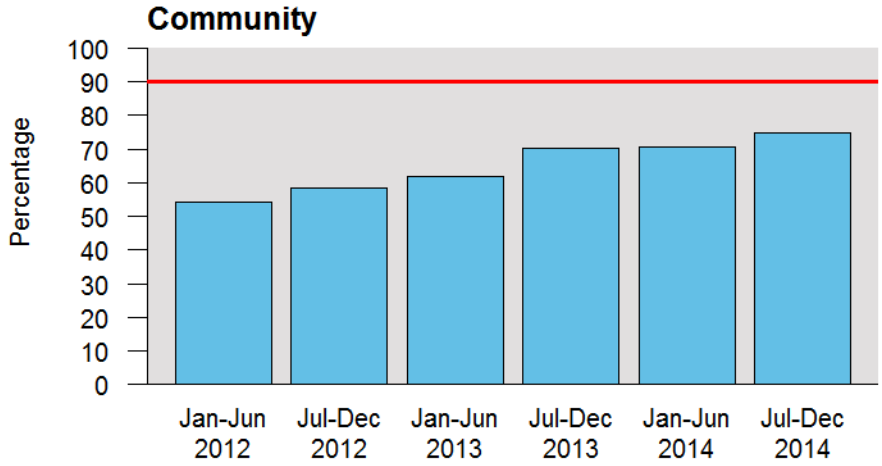
Benchmark 2: This benchmark relates to time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for 3 days or less.

Table 4 Time in unstable phase by setting

Length of unstable phase	Inpatient		Community	
	N	%	N	%
Same day	208	3.2	733	23.1
1 day	2,917	44.6	1,078	33.9
2 days	1,611	24.6	362	11.4
3 days	776	11.9	208	6.5
4-5 days	626	9.6	220	6.9
6-7 days	225	3.4	175	5.5
8-14 days	143	2.2	171	5.4
Greater than 14 days	38	0.6	233	7.3
Total	*6,544*	*100.0*	*3,180*	*100.0*

Figure 8 Percentage of phases that met benchmark 2 over time





2.3 Outcome measure 3 – Change in pain

Pain management is acknowledged as a core business of palliative care services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain. The PCPSS is clinician rated and measures the severity of pain as a clinical problem while the SAS is patient rated and measures distress caused by pain.

There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to be included in the benchmarks.

Scores for PCPSS
0 absent
1 mild
2 moderate
3 severe

Scores for SAS
0 absent
1-3 mild
4-7 moderate
8-10 severe

Interpretation hint:

This outcome measure should be viewed in conjunction with Table 28 to Table 31 and Appendix B.

Benchmarks 3.1 and 3.3: These benchmarks relates to patients who have absent or mild pain at the start of their phase of palliative care. To meet these benchmarks, 90% of phases must end with the patient still experiencing only absent or mild pain.

Benchmarks 3.2 and 3.4: These benchmarks relates to patients who have moderate or severe pain at the start of their phase of palliative care. To meet these benchmarks, 60% of phases must end with the patient's pain reduced to being absent or mild.

Table 5 Summary of outcome measure 3

Benchmark	Inpatient		Community	
	N*	%	N*	%
Benchmark 3.1: PCPSS	15,589	90.9	14,943	84.8
Benchmark 3.2: PCPSS	5,346	57.1	3,933	50.1
Benchmark 3.3: SAS	13,526	88.1	13,991	82.7
Benchmark 3.4: SAS	6,541	52.8	4,879	45.4

*Total number of phases included in this benchmark.

Figure 9 Trends in benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

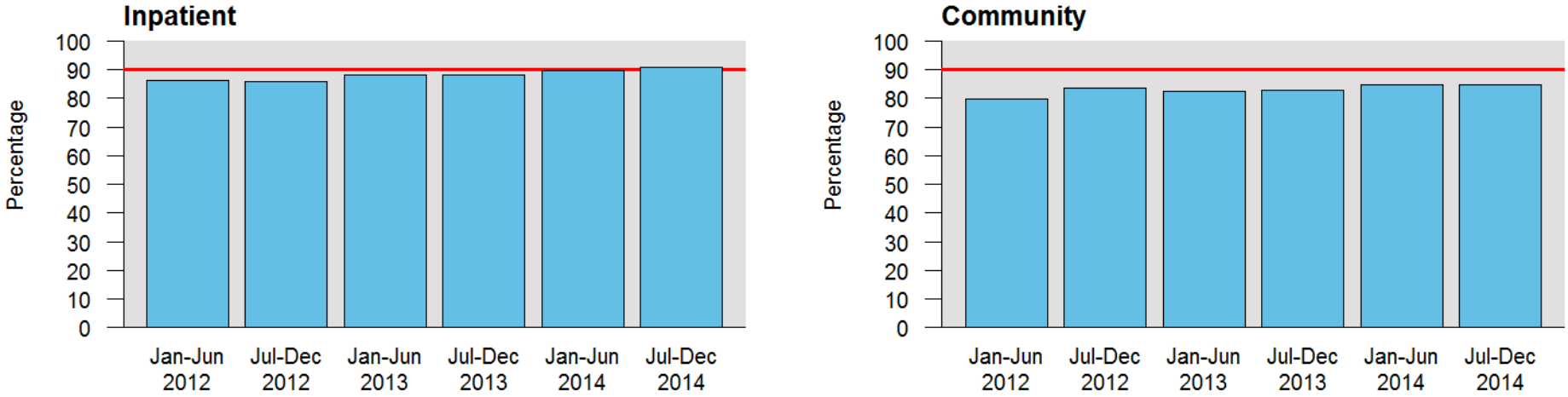


Figure 10 Trends in benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild at phase end by setting

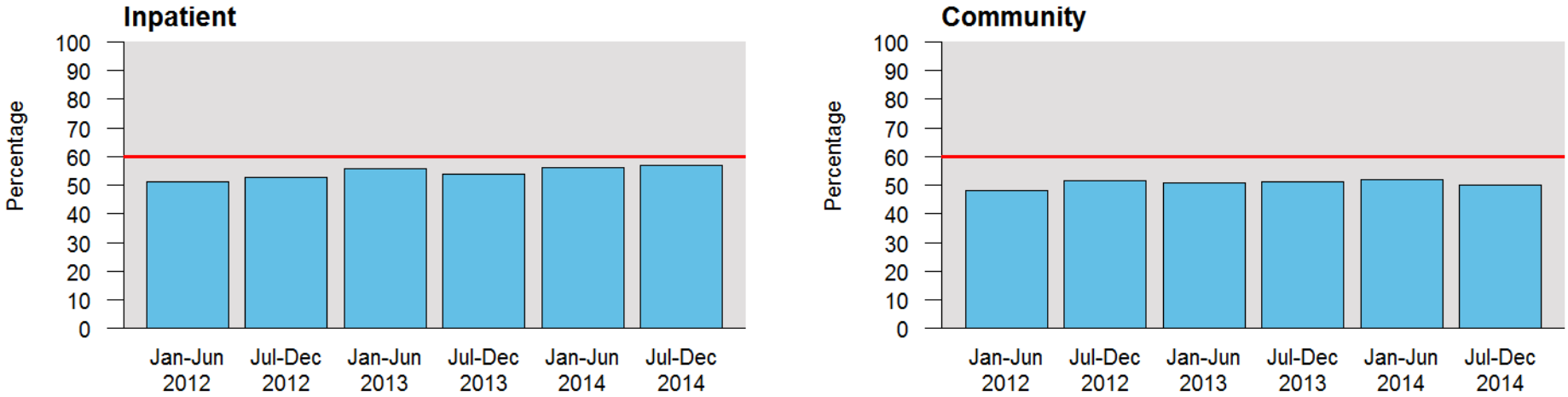


Figure 11 Trends in benchmark 3.3: SAS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

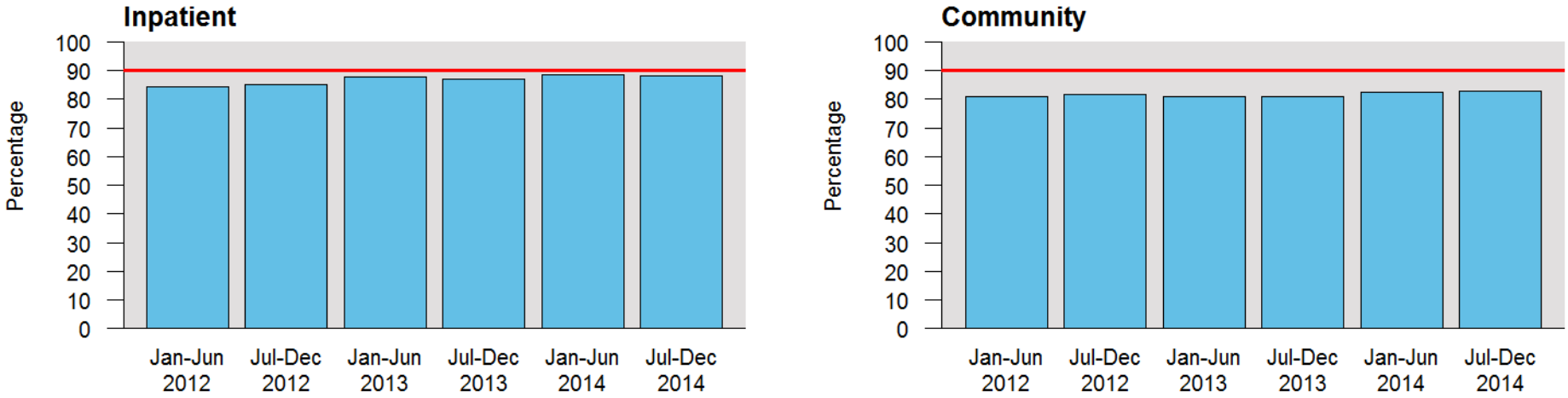
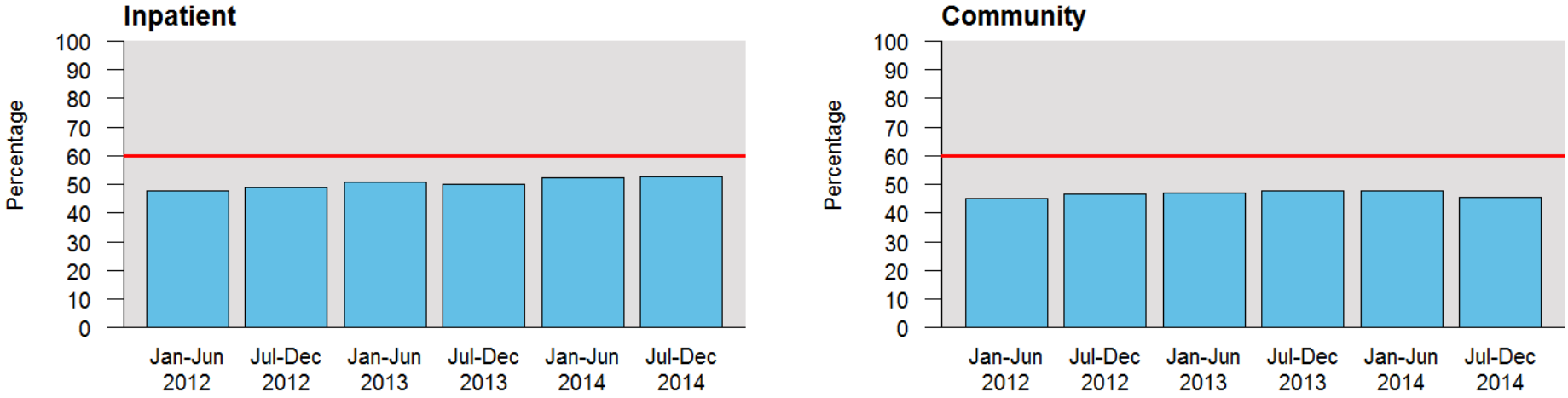


Figure 12 Trends in benchmark 3.4: SAS Patients with moderate/severe pain at phase start, with absent/mild at phase end by setting



2.4 Outcome measure 4 – Change in symptoms relative to the baseline national average (X-CAS)

Outcome measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included in this report and the baseline reference period is January to June 2014. The suite of benchmarks included in outcome measure 4 are generally referred to as X-CAS – *CAS* standing for *Case-mix Adjusted Score*, and the *X* to represent that multiple symptoms are included. As X-CAS looks at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change).

Table 6 Summary of outcome measure 4

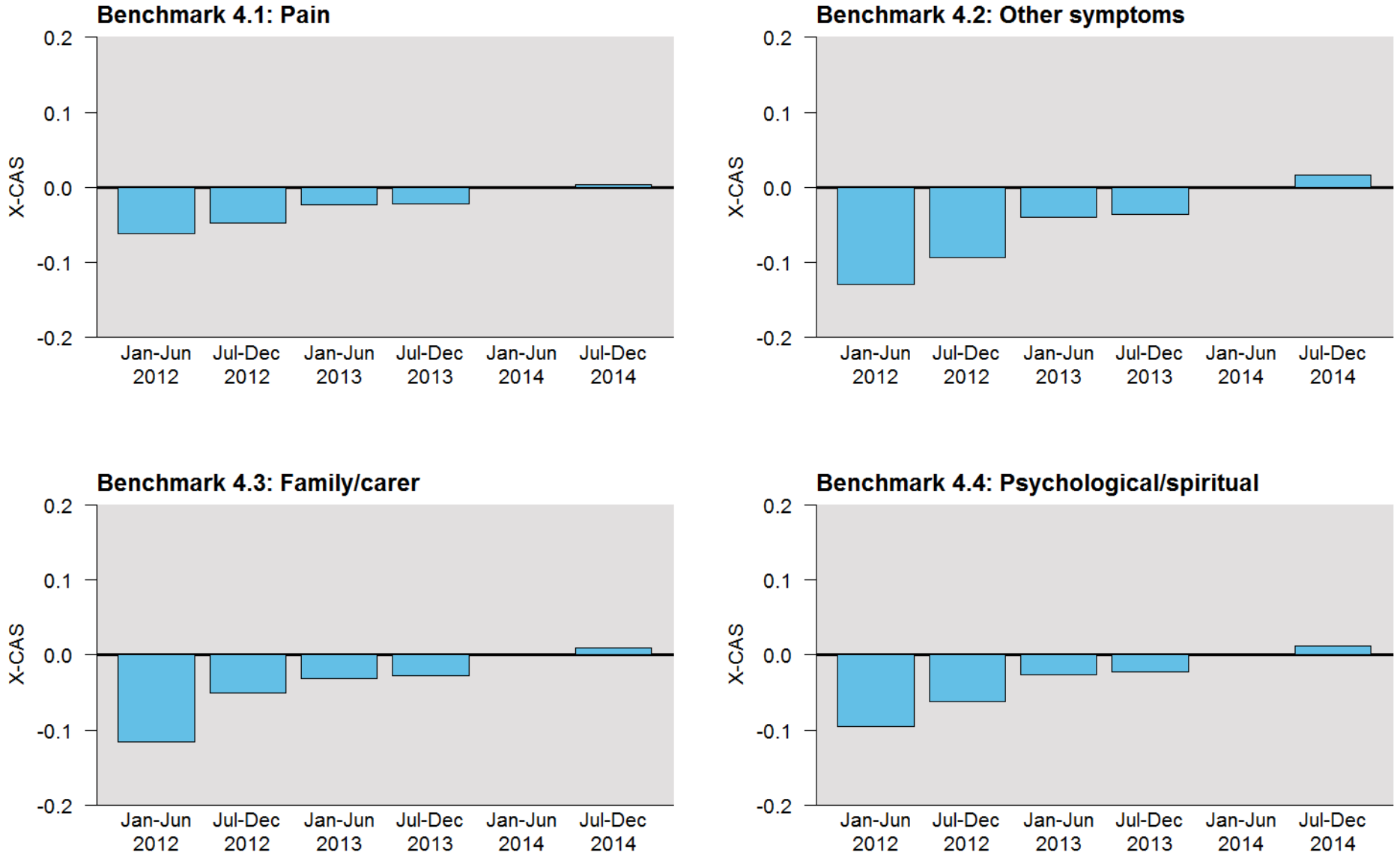
Benchmark: Symptom	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
4.1: PCPSS Pain	0.00	39,811	23,009	57.8
4.2: Other symptoms	0.02	39,616	24,870	62.8
4.3: Family/carer	0.01	39,198	23,943	61.1
4.4: Psychological/spiritual	0.01	40,087	20,819	51.9
4.5: SAS Pain	-0.01	38,937	23,873	61.3
4.6: Nausea	0.02	38,580	31,707	82.2
4.7: Breathing Problems	0.02	38,415	26,699	69.5
4.8: Bowel Problems	0.03	38,024	27,132	71.4

Interpretation hint:

The X-CAS measures are calculated relative to a baseline reference period, which has been updated for this report and is now the period January to June 2014. As a result:

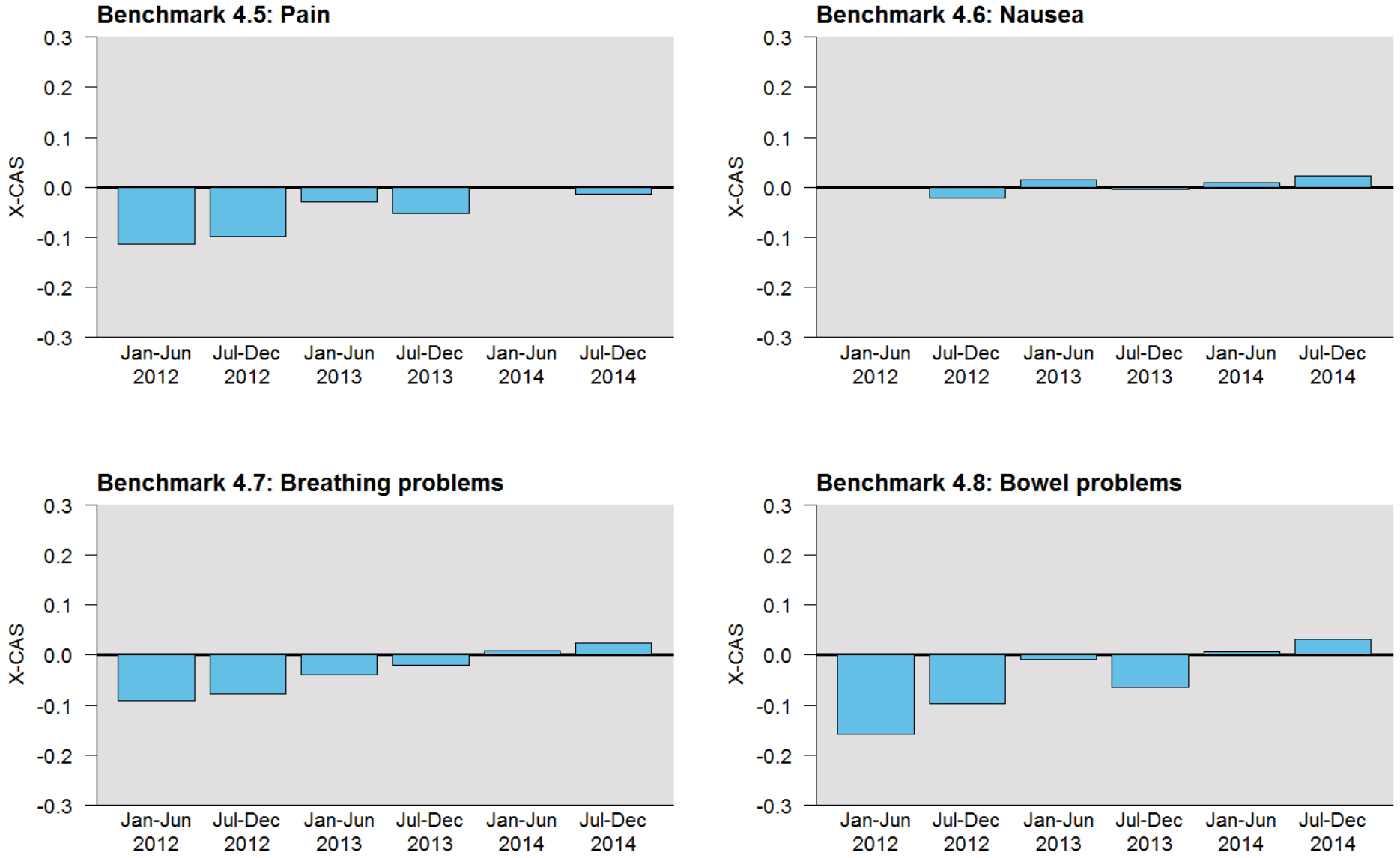
If X-CAS is greater than 0 then on average, patients' change in symptom was better than similar patients in the baseline reference period.
If X-CAS is equal to 0 then on average, patients' change in symptom was about the same as similar patients in the baseline reference period.
If X-CAS is less than 0 then on average, patients' change in symptom was worse than similar patients in the baseline reference period.

Figure 13 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Figure 14 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Section 3 Descriptive analysis

This section provides descriptive information of the data submitted at each of the three levels – patient, episode and phase.

Patient level information describes demographics such as Indigenous status, sex, preferred language and country of birth. This information about the patient provides a context to the episode and phase level information and enhances the meaningfulness of patient outcomes.

Episode level information describes the setting of palliative care service provision. It also includes information relating to the facility/organisation that has referred the patient, how an episode starts/ends and the setting in which the patient died.

Phase level information describes the clinical condition of the patient during the episode, using five clinical assessment tools. These are phase of illness, the patient's functional status and performance, pain and other common symptoms, the patient's psychological/spiritual and family/carer domain.

3.1 Profile of palliative care patients

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family/carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 7 shows the Indigenous status for all patients nationally.

Table 7 Indigenous status

Indigenous status	N	%
Aboriginal but not Torres Strait Islander origin	179	1.0
Torres Strait Islander but not Aboriginal origin	13	0.1
Both Aboriginal and Torres Strait Islander origin	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	17,739	96.9
Not stated/inadequately described	366	2.0
Total	*18,310*	*100.0*

Table 8 shows the breakdown of deaths for all patients nationally for the reporting period. All inpatient deaths are reported in the hospital category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 8 Place of death

Place of death	N	%
Private residence	1,834	20.2
Residential aged care facility	647	7.1
Hospital	6,507	71.7
Not stated/inadequately described	88	1.0
Total	*9,076*	*100.0*

The following two tables show the country of birth and the preferred language respectively for all patients nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 9 is in descending order of the most frequent country of birth according to the 2006 Census (e.g. Italy was the fifth most common country of birth in the 2006 Census). The same approach has been taken with Table 10 (e.g. Greek was the third most frequently spoken language in the 2006 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 9 Country of birth

Country of birth	N	%
Australia	11,458	62.6
England	1,410	7.7
New Zealand	363	2.0
China	170	0.9
Italy	679	3.7
Vietnam	138	0.8
India	139	0.8
Scotland	280	1.5
Philippines	76	0.4
Greece	390	2.1
Germany	233	1.3
South Africa	91	0.5
Malaysia	68	0.4
Netherlands	194	1.1
Lebanon	86	0.5
All other countries	2,270	12.4
Not stated/inadequately described	265	1.4
Total	*18,310*	*100.0*

Table 10 Preferred language

Preferred language	N	%
English	16,528	90.3
Italian	335	1.8
Greek	280	1.5
Chinese[a]	147	0.8
Arabic[b]	100	0.5
Vietnamese[c]	60	0.3
Spanish / Portuguese[d]	35	0.2
Filipino / Indonesian[e]	19	0.1
German[f]	31	0.2
Hindi[g]	22	0.1
Croatian / Macedonian[h]	116	0.6
Korean	16	0.1
Turkish[i]	32	0.2
Polish[j]	30	0.2
Maltese	35	0.2
All other languages	519	2.8
Not stated/inadequately described	5	0.0
Total	*18,310*	*100.0*

(a) Chinese includes: Cantonese, Hakka, Mandarin, Wu and Min Nan; **(b) Middle Eastern Semitic Languages includes:** Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, Mandaean (Mandaic); **(c) Mon-Khmer includes:** Khmer, Mon; **(d) Iberian Romance includes:** Catalan; **(e) Southeast Asian Austronesian Languages includes**: Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo (Hiligaynon), Javanese, Pampangan; **(f) German and Related Languages include:** Letzeburgish, Yiddish; **(g) Indo-Aryan includes:** Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, Fijian Hindustani; **(h) South Slavic includes:** Bosnian, Bulgarian, Serbian, Slovene; **(i) Turkic includes:** Azeri, Tatar, Turkmen, Uygur, Uzbek; **(j) West Slavic includes:** Czech, Slovak

Table 11 and Table 12 present a breakdown of malignant and non-malignant diagnosis. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 58 (0.3%) patients nationally.

Table 11 Primary diagnosis - malignant

Primary diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	220	1.6	1.2
Breast	1,116	7.9	6.1
CNS	281	2.0	1.5
Colorectal	1,610	11.4	8.8
Other GIT	1,406	10.0	7.7
Haematological	837	6.0	4.6
Head and neck	784	5.6	4.3
Lung	3,083	21.9	16.8
Pancreas	898	6.4	4.9
Prostate	960	6.8	5.2
Other urological	592	4.2	3.2
Gynaecological	707	5.0	3.9
Skin	528	3.8	2.9
Unknown primary	404	2.9	2.2
Other primary malignancy	494	3.5	2.7
Malignant – not further defined	143	1.0	0.8
All malignant	*14,063*	*100.0*	*76.8*

Table 12 Primary diagnosis - non-malignant

Primary diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	818	19.5	4.5
HIV/AIDS	12	0.3	0.1
End stage kidney disease	418	10.0	2.3
Stroke	223	5.3	1.2
Motor neurone disease	165	3.9	0.9
Alzheimer's dementia	157	3.7	0.9
Other dementia	242	5.8	1.3
Other neurological disease	355	8.5	1.9
Respiratory failure	749	17.9	4.1
End stage liver disease	159	3.8	0.9
Diabetes and its complications	19	0.5	0.1
Sepsis	94	2.2	0.5
Multiple organ failure	104	2.5	0.6
Other non-malignancy	582	13.9	3.2
Non-malignant – not further defined	92	2.2	0.5
All non-malignant	*4,189*	*100.0*	*22.9*

3.2 Profile of palliative care episodes

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as an inpatient or community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to inpatient) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 13 below presents the number and percentage of episodes by age group and sex. Age has been calculated as at the beginning of each episode.

Table 13 Age group by sex

Age group	Male		Female	
	N	%	N	%
< 15	31	0.2	28	0.3
15 - 24	42	0.3	42	0.4
25 - 34	90	0.7	103	0.9
35 - 44	279	2.2	398	3.6
45 - 54	767	6.2	943	8.5
55 - 64	1,913	15.4	1,748	15.8
65 - 74	3,374	27.2	2,491	22.6
75 - 84	3,793	30.5	2,868	26.0
85+	2,128	17.1	2,411	21.9
Not stated/inadequately described	0	0.0	0	0.0
Total	*12,417*	*100.0*	*11,032*	*100.0*

Note: Records where sex was not stated or inadequately described are excluded from the table.

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 14 presents referral source by setting.

Table 14 Referral source by setting

Referral source	Inpatient		Community	
	N	%	N	%
Public hospital	6,397	52.3	5,458	48.6
Private hospital	1,534	12.5	1,206	10.7
Outpatient clinic	53	0.4	26	0.2
General medical practitioner	386	3.2	1,523	13.6
Specialist medical practitioner	605	4.9	384	3.4
Community-based palliative care agency	2,717	22.2	327	2.9
Community-based service	54	0.4	168	1.5
Residential aged care facility	99	0.8	927	8.3
Self, carer(s), family or friends	156	1.3	371	3.3
Other	163	1.3	302	2.7
Not stated/inadequately described	60	0.5	533	4.7
Total	*12,224*	*100.0*	*11,225*	*100.0*

Table 15 provides a summary of the time between referral to first contact by setting of care. The time from referral to first contact is calculated as the time from the date of referral received to either the date of first contact (if provided) or the episode start date.

Table 15 Referral to first contact by episode setting

Time (in days)	Inpatient		Community	
	N	%	N	%
Same day or following day	11,383	93.1	5,932	52.9
2-7 days	716	5.9	3,711	33.1
8-14 days	61	0.5	883	7.9
Greater than 14 days	61	0.5	697	6.2
Average	1.2	na	2.8	na
Median	1	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Table 16 gives a summary of episode length and Table 17 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 16 Length of episode (in days) summary by setting

Length of episode	Inpatient	Community
Average length of episode	10.6	35.8
Median length of episode	6.0	24.0

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 17 Length of episode (in days) by setting

Length of episode	Inpatient		Community	
	N	%	N	%
Same day	681	5.7	799	8.0
1-2 days	2,304	19.1	597	6.0
3-4 days	1,777	14.8	501	5.0
5-7 days	2,044	17.0	745	7.5
8-14 days	2,586	21.5	1,234	12.3
15-21 days	1,106	9.2	906	9.1
22-30 days	729	6.1	871	8.7
31-60 days	659	5.5	1,736	17.4
61-90 days	106	0.9	834	8.3
Greater than 90 days	50	0.4	1,776	17.8
Total	*12,042*	*100.0*	*9,999*	*100.0*

Note: Only episodes ending during the reporting period are included.

Table 18 How episodes start – inpatient setting

Episode start mode	N	%
Admitted from community*	7,522	61.5
Admitted from another hospital	3,088	25.3
Admitted from acute care in another ward	1,343	11.0
Change from acute care to palliative care – same ward	173	1.4
Other**	92	0.8
Not stated/inadequately described	6	0.0
Total	*12,224*	*100.0*

* includes: admitted from usual accommodation, admitted from other than usual accommodation

** includes: change of sub-acute/non-acute care type and other categories

Table 19 How episodes end – inpatient setting

Episode end mode	N	%
Discharged to community*	4,331	36.0
Discharged to another hospital	877	7.3
Death	6,507	54.0
Change from palliative care to acute care**	74	0.6
Change in sub-acute care type	38	0.3
End of consultative episode – inpatient episode ongoing	98	0.8
Other	111	0.9
Not stated/inadequately described	6	0.0
Total	*12,042*	*100.0*

Note: Only episodes ending during the reporting period are included.

* includes: discharged to usual accommodation, discharged to other than usual accommodation

** includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward

Table 20 How episodes start – community setting

Episode start mode	N	%
Admitted from inpatient palliative care	4,137	36.9
Other*	7,035	62.7
Not stated/inadequately described	53	0.5
Total	*11,225*	*100.0*

*includes: patient was not transferred from being an overnight patient

Table 21 How episodes end – community setting

Episode end mode	N	%
Admitted for inpatient palliative care	2,792	27.9
Admitted for inpatient acute care	2,677	26.8
Admitted to another palliative care service	133	1.3
Admitted to primary health care	611	6.1
Discharged/case closure	1,065	10.7
Death	2,569	25.7
Other	144	1.4
Not stated/inadequately described	8	0.1
Total	*9,999*	*100.0*

Note: Only episodes ending during the reporting period are included.

3.3 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix D for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

Table 22 Number of phases by phase type and setting

Phase type	Inpatient		Community	
	N	%	N	%
Stable	7,330	25.8	9,334	37.2
Unstable	6,544	23.0	3,180	12.7
Deteriorating	8,978	31.6	10,424	41.6
Terminal	5,557	19.6	2,120	8.5
Total	*28,409*	*100.0*	*25,058*	*100.0*

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 23 Average phase length (in days) by phase type and setting

Phase type	Inpatient	Community
Stable	6.9	19.8
Unstable	2.3	4.4
Deteriorating	5.5	12.7
Terminal	2.1	3.0

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

Table 24 presents information relating to the manner in which stable phases ended. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 15 summarises the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression. The phase progression information is derived by PCOC.

Similar information is presented for the unstable (Table 25, Figure 16), deteriorating (Table 26, Figure 17) and terminal (Table 27, Figure 18) phases on the following pages.

Table 24 How stable phases end – by setting

How stable phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	3,681	50.2	6,076	65.1
Discharge/case closure	3,539	48.3	2,972	31.8
Died	103	1.4	247	2.6
Not stated/inadequately described	7	0.1	39	0.4
Total	*7,330*	*100.0*	*9,334*	*100.0*

Figure 15 Stable phase progression

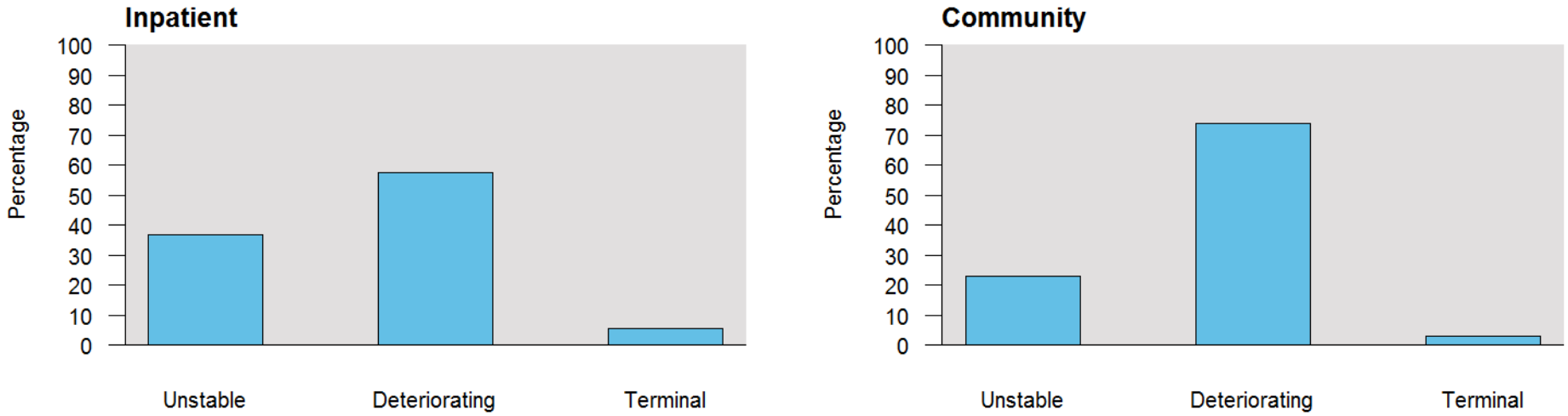


Table 25 How unstable phases end – by setting

How unstable phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	6,022	92.0	2,147	67.5
Discharge/case closure	367	5.6	963	30.3
Died	148	2.3	63	2.0
Not stated/inadequately described	7	0.1	7	0.2
Total	*6,544*	*100.0*	*3,180*	*100.0*

Figure 16 Unstable phase progression

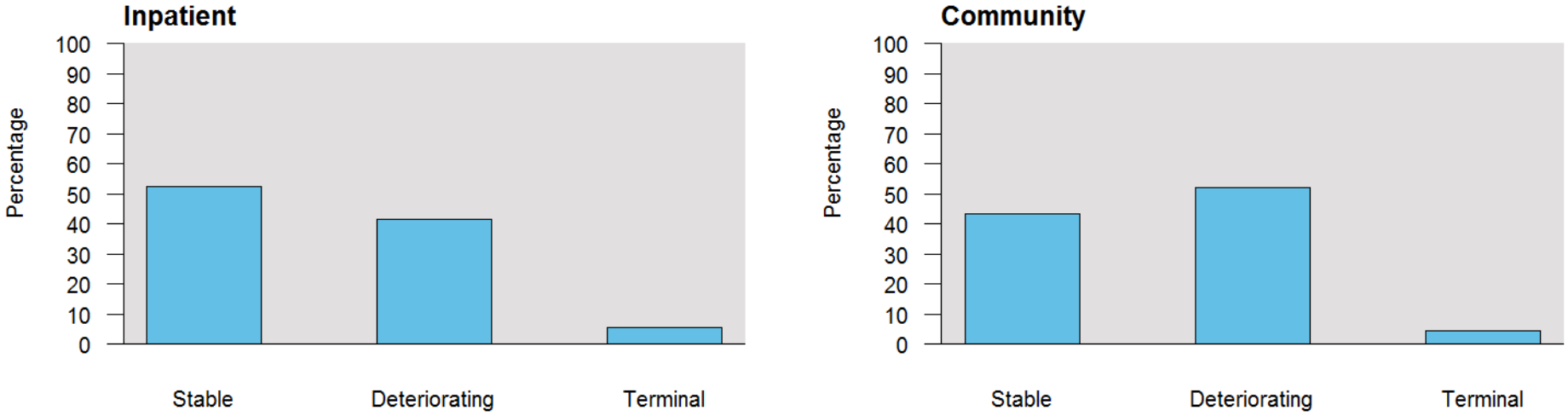


Table 26 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	6,444	71.8	6,442	61.8
Discharge/case closure	1,501	16.7	3,209	30.8
Died	1,027	11.4	762	7.3
Not stated/inadequately described	6	0.1	11	0.1
Total	*8,978*	*100.0*	*10,424*	*100.0*

Figure 17 Deteriorating phase progression

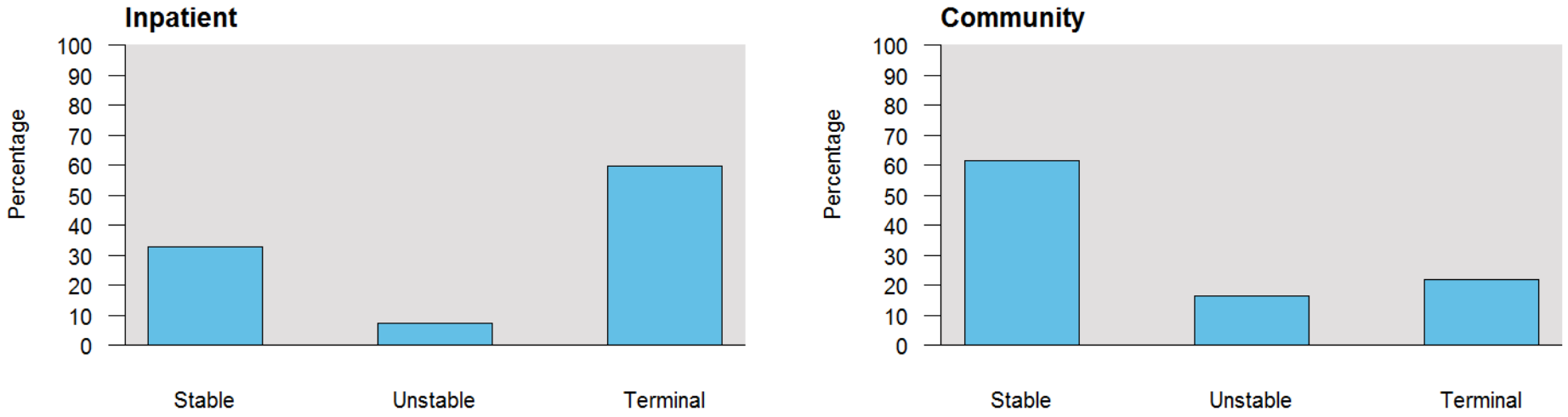
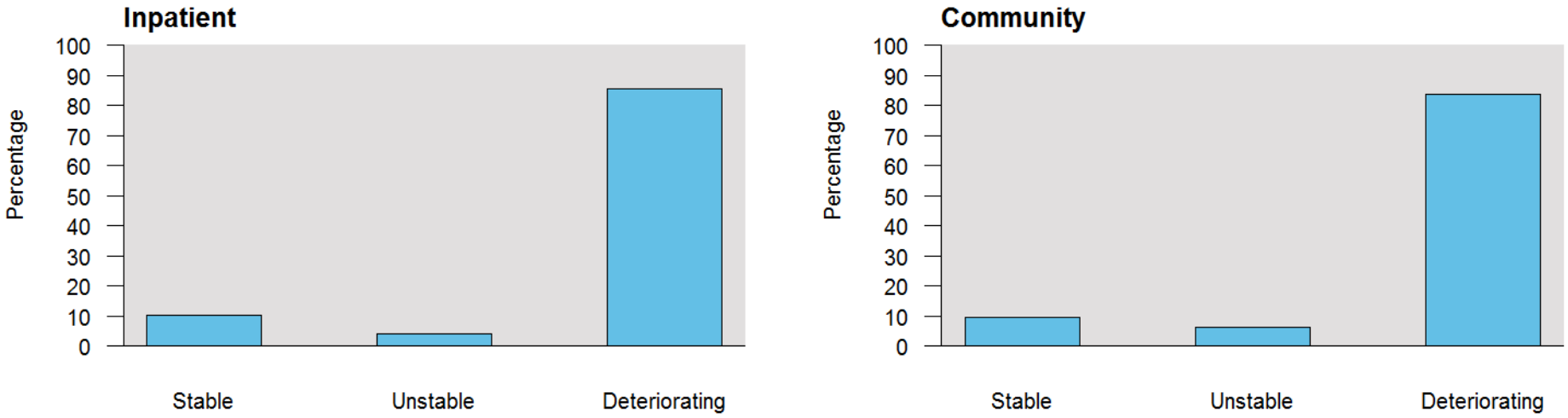


Table 27 How terminal phases end – by setting

How terminal phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	215	3.9	330	15.6
Discharge/case closure	106	1.9	241	11.4
Died	5,236	94.2	1,548	73.0
Not stated/inadequately described	0	0.0	1	0.0
Total	*5,557*	*100.0*	*2,120*	*100.0*

Figure 18 Terminal phase progression



The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological/spiritual and family/carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 28 and Table 29 show the percentage scores for the inpatient and community settings respectively.

Table 28 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	48.8	37.6	11.0	2.5
	Other symptoms	25.8	51.9	19.1	3.3
	Psychological/spiritual	32.7	52.6	12.2	2.5
	Family/carer	40.6	43.1	12.8	3.4
Unstable	Pain	30.5	30.9	25.6	12.9
	Other symptoms	13.8	34.1	38.3	13.8
	Psychological/spiritual	23.8	44.1	24.8	7.4
	Family/carer	26.1	40.8	24.2	8.9
Deteriorating	Pain	38.4	35.9	19.7	5.9
	Other symptoms	15.3	40.8	33.5	10.4
	Psychological/spiritual	24.9	47.8	21.6	5.7
	Family/carer	27.6	41.6	23.0	7.8
Terminal	Pain	48.1	32.7	14.0	5.1
	Other symptoms	33.6	35.0	21.8	9.6
	Psychological/spiritual	51.1	31.8	12.5	4.6
	Family/carer	21.9	35.6	30.2	12.4

Table 29 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	41.0	50.8	7.6	0.6
	Other symptoms	14.9	66.3	17.5	1.3
	Psychological/spiritual	30.2	58.5	10.2	1.1
	Family/carer	31.1	53.6	13.5	1.7
Unstable	Pain	18.3	28.7	33.6	19.4
	Other symptoms	5.4	28.0	48.4	18.3
	Psychological/spiritual	12.1	45.6	34.4	7.9
	Family/carer	14.1	34.8	39.3	11.8
Deteriorating	Pain	28.4	49.3	19.5	2.8
	Other symptoms	7.0	48.7	39.2	5.1
	Psychological/spiritual	18.4	58.0	20.8	2.9
	Family/carer	19.1	47.9	28.5	4.5
Terminal	Pain	35.7	44.4	15.8	4.1
	Other symptoms	20.9	40.9	29.6	8.6
	Psychological/spiritual	40.0	42.0	15.0	3.1
	Family/carer	12.6	40.1	36.8	10.5

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no problems to 10 - worst possible problems. The SAS reports on seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 30 and Table 31 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Additional information on the SAS profile by phase can be found in Appendix B.

Table 30 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	67.8	18.1	11.5	2.6
	Appetite problems	55.0	23.3	17.7	4.0
	Nausea	79.7	13.2	6.0	1.0
	Bowel problems	61.8	21.7	13.5	3.1
	Breathing problems	64.8	18.2	13.6	3.4
	Fatigue	27.3	25.0	38.4	9.3
	Pain	46.3	31.9	18.9	3.0
Unstable	Difficulty sleeping	57.6	17.5	18.7	6.1
	Appetite problems	41.8	22.4	25.8	10.0
	Nausea	68.3	14.3	12.2	5.3
	Bowel problems	50.9	21.2	20.7	7.3
	Breathing problems	55.2	17.2	18.6	8.9
	Fatigue	21.2	17.1	43.4	18.3
	Pain	30.9	24.6	31.8	12.7
Deteriorating	Difficulty sleeping	67.5	15.3	14.0	3.2
	Appetite problems	50.9	19.0	22.1	7.9
	Nausea	76.2	12.3	9.2	2.3
	Bowel problems	59.5	20.3	15.9	4.3
	Breathing problems	55.5	18.1	18.6	7.8
	Fatigue	24.8	14.7	41.0	19.5
	Pain	38.2	29.1	26.7	6.0
Terminal	Difficulty sleeping	90.0	4.8	4.2	1.1
	Appetite problems	87.8	3.7	5.0	3.5
	Nausea	93.0	3.7	2.4	0.9
	Bowel problems	84.4	7.7	5.8	2.2
	Breathing problems	67.6	12.4	13.4	6.6
	Fatigue	71.0	4.7	12.0	12.3
	Pain	56.3	22.4	16.9	4.3

Table 31 Profile of SAS scores at beginning of phase by phase type –community setting (percentages)

Phase Type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	63.5	25.9	9.6	0.9
	Appetite problems	48.4	33.3	16.4	1.9
	Nausea	80.5	15.9	3.3	0.3
	Bowel problems	67.7	24.3	7.1	0.9
	Breathing problems	54.4	30.2	13.6	1.7
	Fatigue	15.6	34.3	44.6	5.5
	Pain	44.3	41.8	12.8	1.1
Unstable	Difficulty sleeping	44.7	25.6	23.8	5.9
	Appetite problems	34.9	26.4	29.5	9.2
	Nausea	61.0	17.6	15.1	6.2
	Bowel problems	52.9	26.4	15.4	5.3
	Breathing problems	47.2	26.2	20.0	6.6
	Fatigue	10.0	18.2	52.6	19.2
	Pain	20.3	24.1	35.9	19.7
Deteriorating	Difficulty sleeping	57.0	27.5	13.5	2.0
	Appetite problems	39.0	30.4	25.7	5.0
	Nausea	73.0	18.7	7.3	1.1
	Bowel problems	61.7	25.9	10.6	1.7
	Breathing problems	47.6	30.7	18.7	3.1
	Fatigue	10.6	22.3	54.5	12.7
	Pain	32.3	40.9	23.2	3.6
Terminal	Difficulty sleeping	75.7	13.6	8.4	2.2
	Appetite problems	78.1	6.6	7.3	8.0
	Nausea	85.0	8.9	4.9	1.2
	Bowel problems	74.1	15.7	8.4	1.8
	Breathing problems	55.5	22.8	17.0	4.6
	Fatigue	57.4	5.0	13.7	23.9
	Pain	40.9	35.5	19.6	4.0

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 32 shows the data for the AKPS at phase start.

Table 32 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment	Inpatient		Community	
	N	%	N	%
10 - Comatose or barely rousable	2,907	10.2	822	3.3
20 - Totally bedfast and requiring extensive nursing care	6,243	22.0	2,428	9.7
30 - Almost completely bedfast	3,860	13.6	1,682	6.7
40 - In bed more than 50% of the time	5,151	18.1	3,161	12.6
50 - Requires considerable assistance	4,855	17.1	5,864	23.4
60 - Requires occasional assistance	2,947	10.4	6,317	25.2
70 - Cares for self	706	2.5	3,322	13.3
80 - Normal activity with effort	215	0.8	699	2.8
90 - Able to carry on normal activity; minor signs or symptoms	56	0.2	155	0.6
100 - Normal; no complaints; no evidence of disease	1	0.0	13	0.1
Not stated/inadequately described	1,468	5.2	595	2.4
Total	*28,409*	*100.0*	*25,058*	*100.0*

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Figure 19 and Figure 20 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients and community patients. The total score on the RUG-ADL ranges from a minimum of 4 (lowest level of functional dependency) to a maximum of 18 (highest level of functional dependency).

AKPS & RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements.

Figure 19 Total RUG-ADL at beginning of phase by phase type – inpatient setting

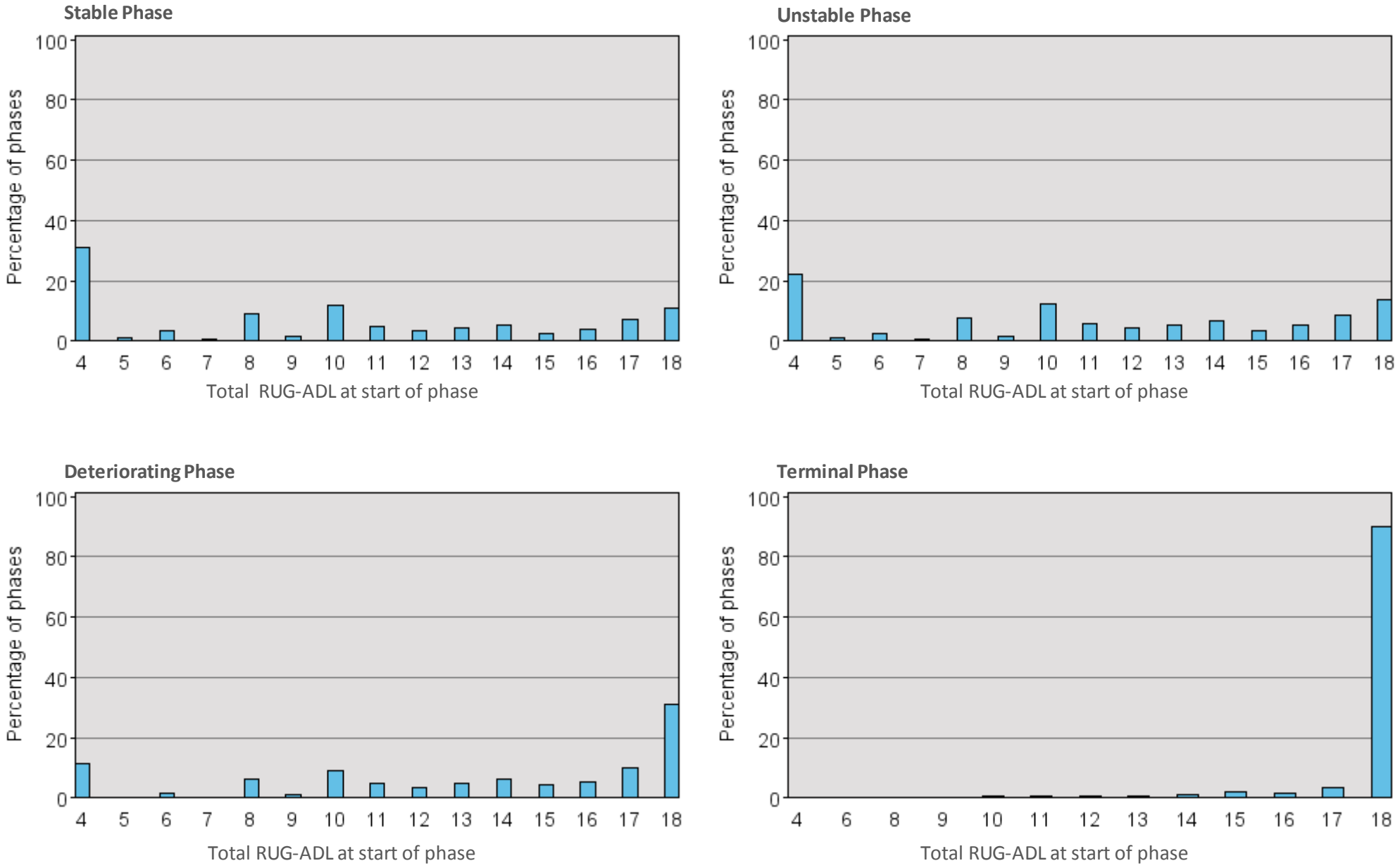
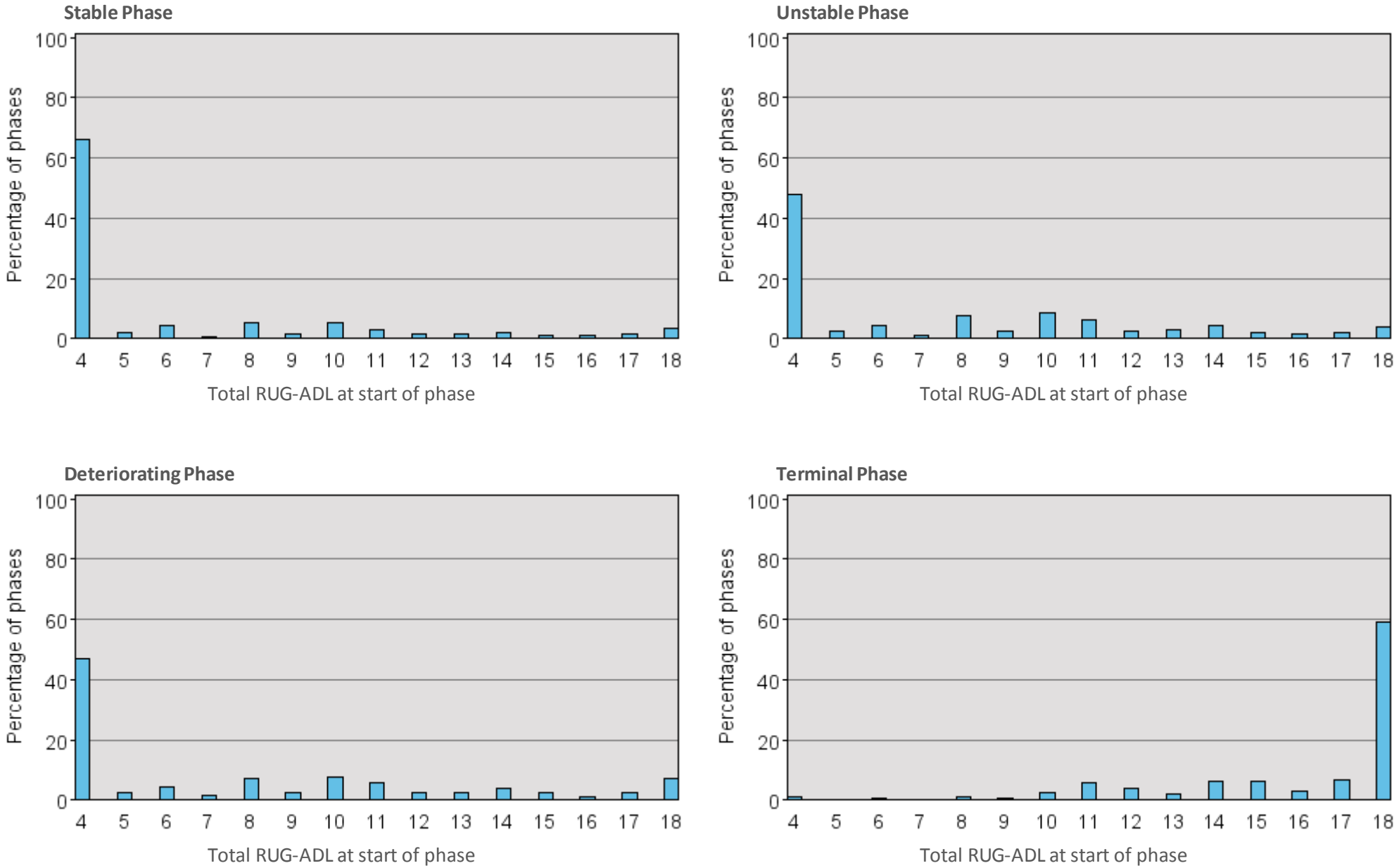


Figure 20 Total RUG-ADL at beginning of phase by phase type – community setting



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 18,310 patients who between them had 23,449 episodes of care and 53,467 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix B contains a more detailed explanation of this process). Table 33 shows the number of patients, episodes and phases included in this report.

A consequence of the data scoping method is that it is likely that not all phases related to a particular episode are included in this report. Hence, the average number of phases per episode calculation shown in Table 33 may be an underestimate (due to episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

Table 33 Number and percentage of patients, episodes and phases by setting

	Inpatient	Community	Total
Number of patients*	10,311	8,963	18,310
Number of episodes	12,224	11,225	23,449
Number of phases**	28,409	25,058	53,467
Percentage of patients*	56.3	49.0	100
Percentage of episodes	52.1	47.9	100
Percentage of phases	53.1	46.9	100
Average number of phases per episode***	2.3	2.0	2.2

* Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.
** Bereavement phases are excluded from this count.
*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 34 shows the number of completed episodes and phases by setting for each month in the current reporting period. This table identifies any change in patient numbers during the reporting period.

Table 34 Number of completed episodes and phases by month and setting

		Jul	Aug	Sep	Oct	Nov	Dec
Inpatient	No. of completed episodes	2,067	2,021	2,058	2,095	1,948	1,853
	No. of completed phases	5,034	4,906	4,885	4,808	4,662	4,114
Community	No. of completed episodes	1,808	1,714	1,599	1,748	1,625	1,505
	No. of completed phases	4,451	4,156	4,082	4,253	4,133	3,983

A2 Data item completion

As shown in Table 35, Table 36 and Table 37 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

Table 35 Item completion (per cent complete) - patient level

Data item	Total
Date of birth	100.0
Sex	100.0
Indigenous status	98.0
Country of birth	98.5
Preferred language	100.0
Primary diagnosis	99.7

Note: This table is not split by setting to be consistent with the patient level analysis throughout this report.

Table 36 Item completion by setting (per cent complete) - episode level

Data item	Inpatient	Community	Total
Date of first contact	100.0	100.0	100.0
Referral date	100.0	100.0	100.0
Referral source	99.5	95.3	97.5
Date ready for care	94.7	100.0	97.2
Mode of episode start	100.0	99.5	99.7
Accommodation at episode start	99.9	96.3	97.7
Episode end date*	99.8	92.2	96.2
Mode of episode end	100.0	99.9	99.9
Accommodation at episode end	98.6	91.8	96.5
Place of death	na	96.6	96.6

* Episode end date item completion may be affected by open episodes.

Table 37 Item completion by setting (per cent complete) - phase level

Data item	Sub-Category (where applicable)	At phase start			At discharge		
		Inpatient	Community	Total	Inpatient	Community	Total
RUG-ADL	Bed mobility	99.7	97.4	98.6	92.3	63.2	75.7
	Toileting	99.7	97.3	98.6	92.3	63.2	75.6
	Transfers	99.7	96.7	98.3	92.3	63.2	75.6
	Eating	99.5	95.6	97.7	92.3	62.8	75.4
PCPSS	Pain	97.8	97.5	97.6	91.1	62.9	75.0
	Other symptom	97.6	96.7	97.2	91.1	62.5	74.7
	Psychological/spiritual	99.4	97.2	98.4	92.2	62.8	75.4
	Family/carer	97.3	96.0	96.7	88.0	62.2	73.2
SAS	Difficulty sleeping	92.9	93.8	93.3	81.3	60.4	69.3
	Appetite problems	93.1	95.0	94.0	81.5	61.7	70.2
	Nausea	93.2	96.4	94.7	81.7	62.4	70.6
	Bowel problems	93.0	95.0	93.9	81.5	61.3	69.9
	Breathing problems	93.2	96.0	94.5	81.6	62.0	70.4
	Fatigue	93.2	96.1	94.5	81.6	62.3	70.5
	Pain	93.2	97.3	95.1	81.6	63.0	71.0
AKPS	-	94.8	97.6	96.1	89.7	63.2	74.5

Data item	Inpatient	Community	Total
Phase End Reason	99.9	99.7	99.8

Appendix B Additional information on profile of SAS scores

Figure 21 Profile of SAS Score by symptom – inpatient setting

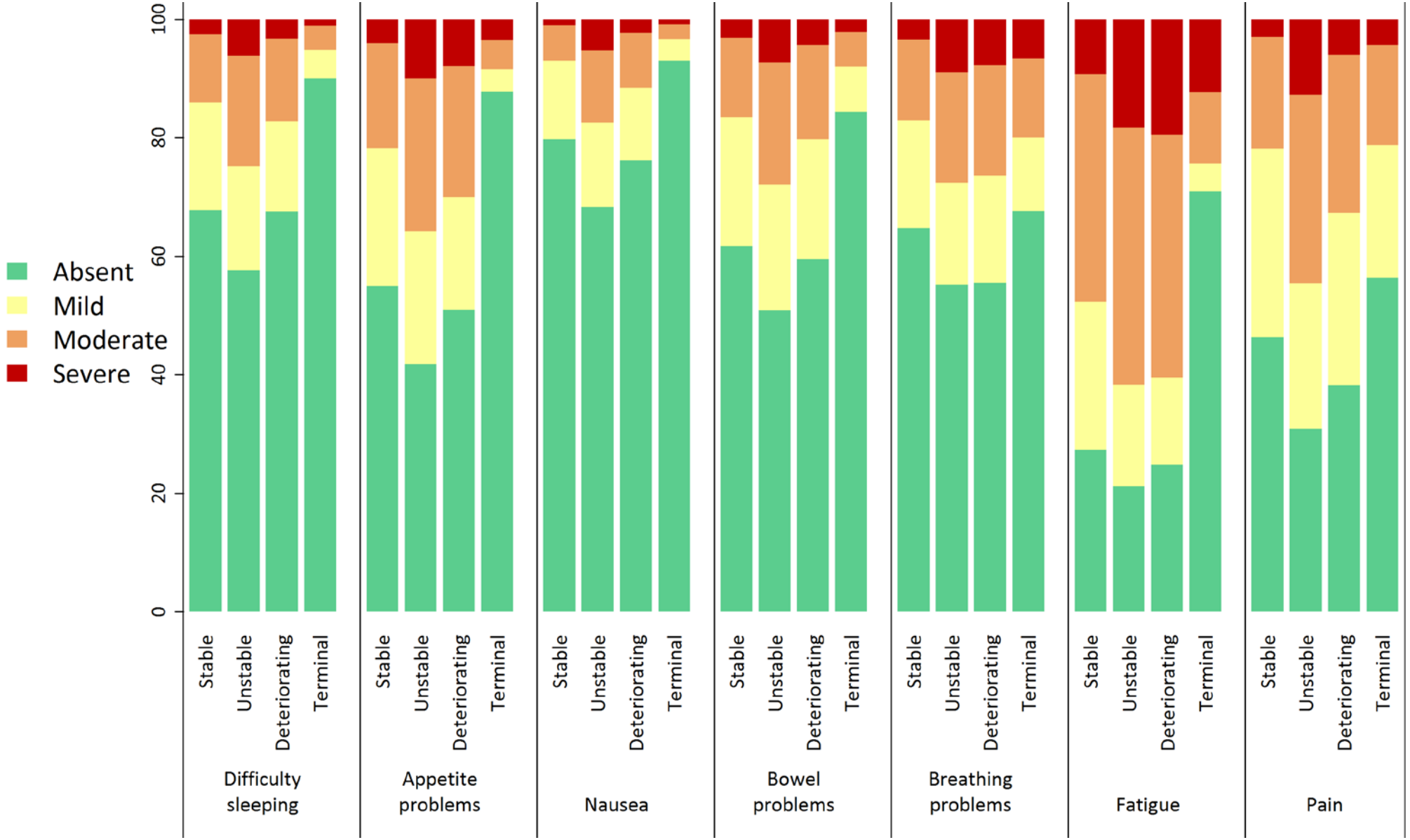
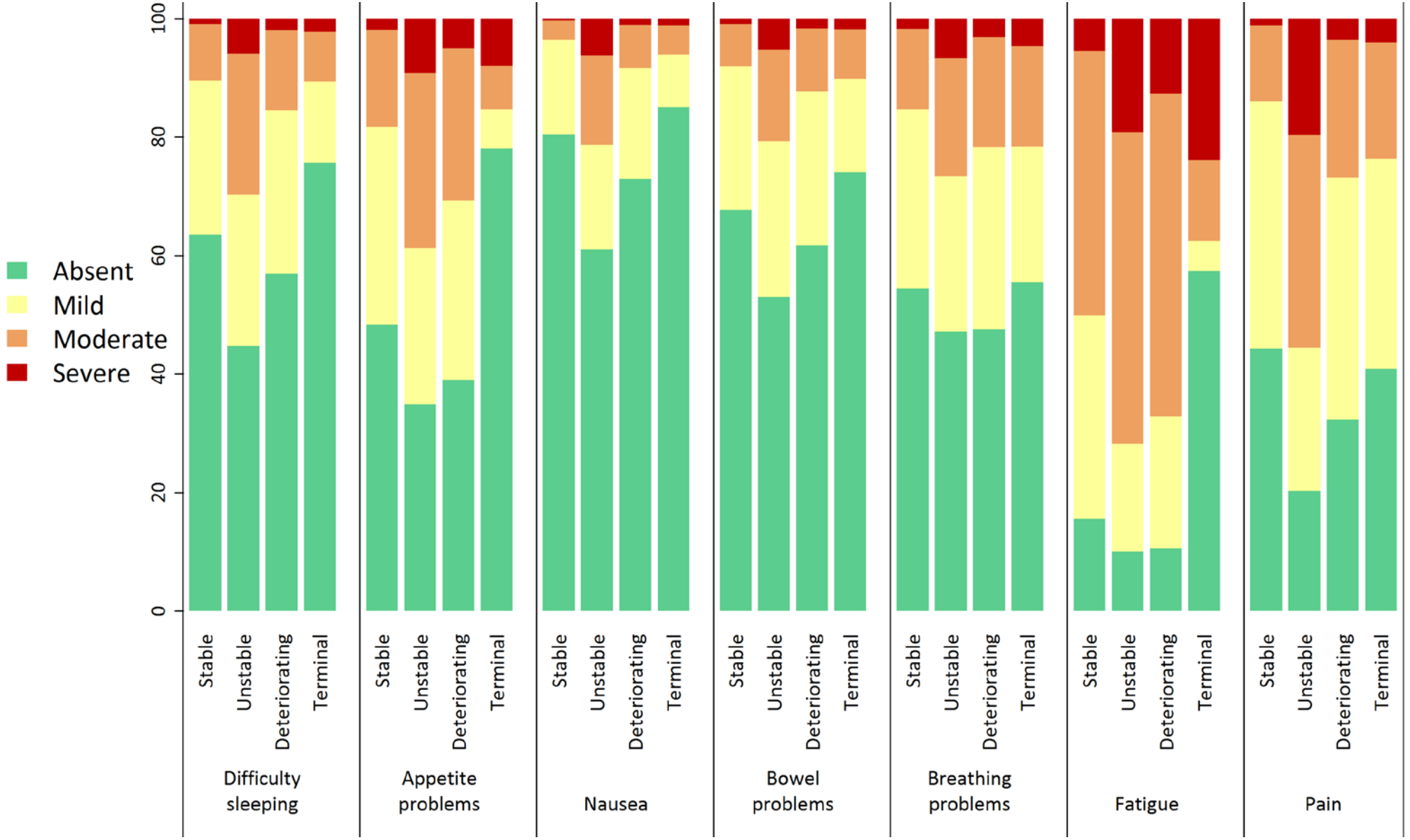


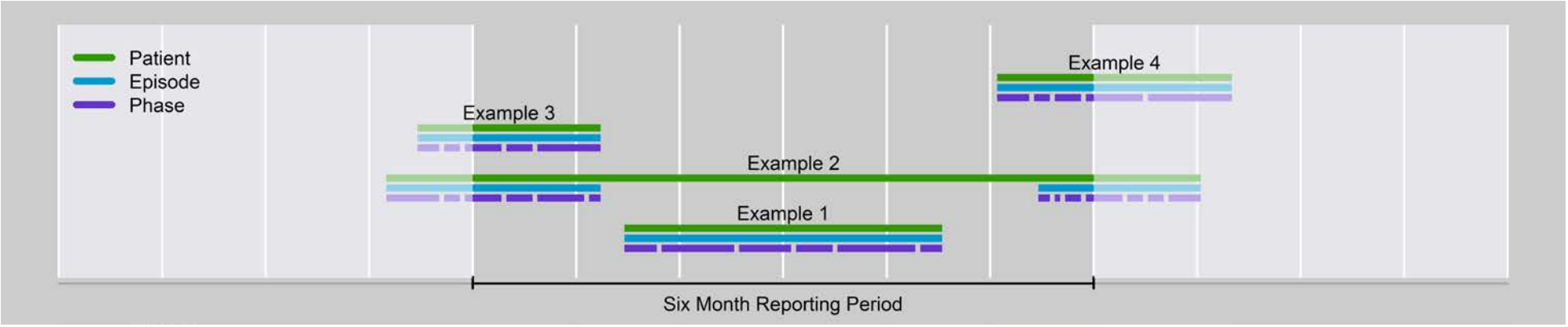
Figure 22 Profile of SAS Score by symptom – community setting



Appendix C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 23 below displays four examples to help visualize this process.

Figure 23 Diagram of the PCOC data scoping method



In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

In Example 3, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

Appendix D Palliative Care Phase definitions

START	END
1. Stable	
Patient problems and symptoms are adequately controlled by established plan of care **and** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care.
2. Unstable	
An urgent change in the plan of care or emergency treatment is required **because** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and/or** ▪ Family/ carers circumstances change suddenly impacting on patient care.	▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and/or** ▪ Death is likely within days (i.e. patient is now terminal).
3. Deteriorating	
The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and** ▪ Patient experiences a gradual worsening of existing problem **and/or** ▪ Patient experiences a new but anticipated problem **and/or** ▪ Family/carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and/or** ▪ Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
4. Terminal	
Death is likely within days.	▪ Patient dies **or** ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
5. Bereavement – post death support	
▪ The patient has died ▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record.	▪ Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

Acknowledgements

Contributions PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

Disclaimer PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.

Suggested Citation Holloway A, Bird S, Clapham S, Quinsey K, Allingham S, and Foskett L (2015) *National Report on Patient Outcomes in Palliative Care in Australia, July – December 2014.* Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong